



Wilms Tumor Overview

The information that follows is an overview of this type of cancer. It is based on the more detailed information in our document, *Wilms Tumor*. This document and other information can be obtained by calling 1-800-227-2345 or visiting our Web site at www.cancer.org.

What is cancer?

The body is made up of trillions of living cells. Normal body cells grow, divide, and die in an orderly way. During the early years of a person's life, normal cells divide faster to allow the person to grow. After the person becomes an adult, most cells divide only to replace worn-out, damaged, or dying cells.

Cancer begins when cells in a part of the body start to grow out of control. There are many kinds of cancer, but they all start because of this out-of-control growth of abnormal cells.

Cancer cell growth is different from normal cell growth. Instead of dying, cancer cells keep on growing and form new cancer cells. These cancer cells can grow into (invade) other tissues, something that normal cells cannot do. Being able to grow out of control and invade other tissues are what makes a cell a cancer cell.

In most cases the cancer cells form a tumor. But some cancers, like leukemia, rarely form tumors. Instead, these cancer cells are in the blood and bone marrow.

When cancer cells get into the bloodstream or lymph vessels, they can travel to other parts of the body. There they begin to grow and form new tumors that replace normal tissue. This process is called *metastasis* (muh-**tas**-tuh-sis).

No matter where a cancer may spread, it is always named for the place where it started. For instance, breast cancer that has spread to the liver is still called breast cancer, not liver cancer. Likewise, prostate cancer that has spread to the bone is called metastatic prostate cancer, not bone cancer.

Different types of cancer can behave very differently. For example, lung cancer and breast cancer are very different diseases. They grow at different rates and respond to different treatments. That is why people with cancer need treatment that is aimed at their own kind of cancer.

Not all tumors are cancerous. Tumors that aren't cancer are called *benign* (be-**nine**). Benign tumors can cause problems – they can grow very large and press on healthy organs and tissues. But they cannot grow into other tissues. Because of this, they also can't spread to other parts of the body (metastasize). These tumors are almost never life threatening.

What are the differences between cancers in adults and those in children?

The types of cancers that children get are different from the types found in adults. There are exceptions, but as a rule children tend to withstand and respond better to treatment like chemotherapy. But chemotherapy can have some long-term side effects. So children who have had treatment for cancer need to be followed carefully for the rest of their lives.

Children with cancer and their families have special needs that are best met by children's cancer centers. In these centers, teams of experts with experience in treating children provide the best chance for a cure. The team can include (besides doctors and nurses) psychologists, social workers, child life specialists, educators, and others.

Since the 1960s most children with cancer have been treated at these special centers. In the United States, most children with cancer are treated at a children's cancer center that is a member of the Children's Oncology Group (COG). All of these centers are associated with a university or children's hospital.

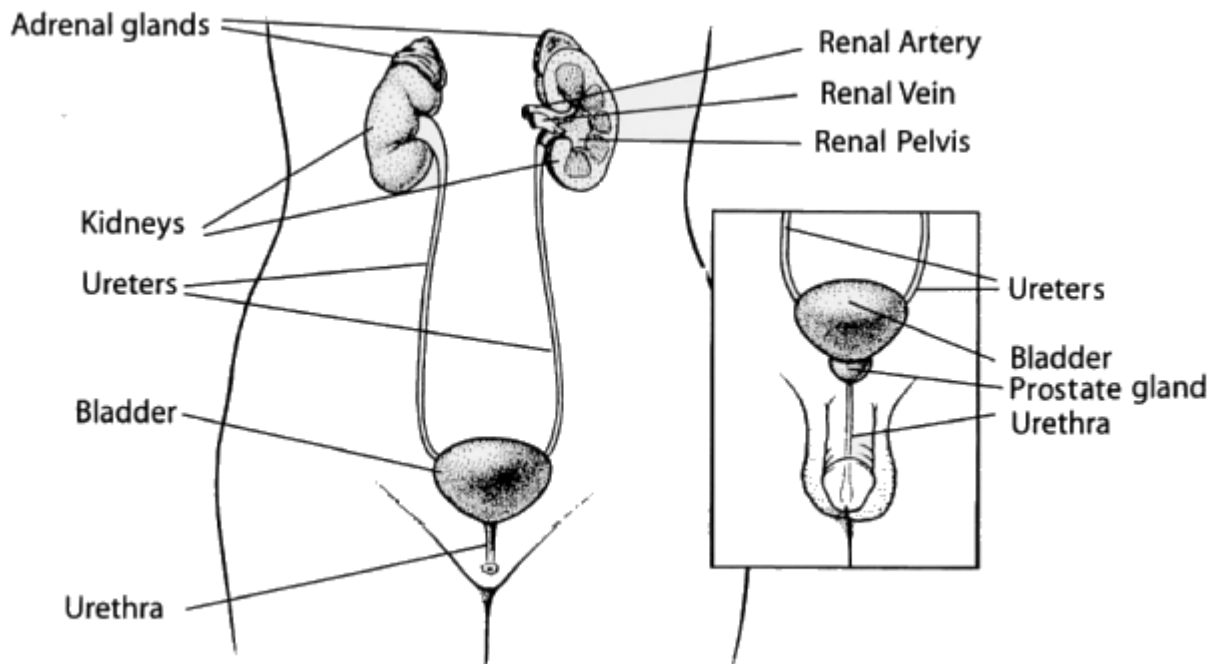
What is Wilms tumor?

Wilms tumor is a type of cancer that starts in the kidneys. It is the most common type of kidney cancer in children. It is named for Max Wilms, the German doctor who first wrote about it in 1899.

About the kidneys

To understand Wilms tumor, it helps to know something about the kidneys.

The kidneys are 2 bean-shaped organs fixed to the back of the belly (abdomen). They are shown in the picture below. Each kidney is about the size of a fist. One kidney is just to the left and the other just to the right of the backbone. The lower rib cage protects the kidneys.



The kidney's main job is to filter the blood and get rid of extra water, salt, and waste products in the form of urine. Urine leaves the kidneys through long slender tubes called ureters. Each kidney has a single ureter. The ureters empty into the bladder where urine is stored until it is passed out of the body.

The kidneys help control blood pressure. They also help make sure the body has enough red blood cells. They do this by making a hormone (called *erythropoietin*), that tells the bone marrow to make more red blood cells.

Although the kidneys are important, people can get by with just one kidney. Today many people are living normal, healthy lives with just one kidney.

Wilms tumors

Wilms tumors usually form only in one kidney, but in a small number of cases they form in both. Wilms tumors are often found only after they have grown quite large, but most are found before they have spread to other organs. The average weight of a newly-found Wilms tumor is about a pound. That's much larger than the kidney it started in.

Even though doctors may think a child has a cancer such as Wilms tumor based on a physical exam or other tests, they cannot be certain until a sample of the tumor is looked at under a microscope.

Types of Wilms tumors

There are 2 main types of Wilms tumors. The type depends on how the cells look under a microscope (this is called their *histology*).

Favorable histology: Cells that look favorable show no anaplasia (see below), although they don't look quite normal. The chance of cure is good. More than 9 out of 10 Wilms tumors have are of this type.

Unfavorable histology: If a tumor looks unfavorable, it means that the centers of the cells are very large and not the right shape. This is called *anaplasia*. The more anaplasia is found, the harder it is to cure children with these tumors.

Rarely, children can have other kinds of kidney cancer. **The information here is only about Wilms tumor and not other kinds of kidney cancer.**

How many children get Wilms tumor?

About 500 new cases of Wilms tumors are found each year in the United States. About 5% of all cancers in children are Wilms tumors. Wilms tumor occurs most often in very young children and is not common in children after the age of 6. It is slightly more common among African Americans and among girls. The reason for this is not known.

What are the risk factors for Wilms tumor?

Researchers are learning more about how changes in the genes and other factors work to cause Wilms tumors and other cancers. They don't know exactly why some children get Wilms tumors, but they have made great progress in learning what happens as the kidneys form in a baby. When this process goes wrong, Wilms tumor can be the result.

The kidneys develop very early as babies grow in the womb. Sometimes a mistake happens as the kidney grows. Some of the cells don't mature. Instead, they stay like early (fetal) cells. Small or large clusters of these early kidney cells can still be there after the baby is born. Most often, these cells will mature by the time the child is 3 or 4 years old. But if this doesn't happen, the cells may begin to grow out of control. The result could be a Wilms tumor.

Risk factors

A *risk factor* is something that affects a person's chance of having a disease such as cancer. Some risk factors, like smoking, can be controlled. Others, like a person's age or race, can't be changed. Different cancers have different risk factors. But risk factors don't tell us everything. Having a risk factor, or even several, does not mean that a person will get the disease. And many people get cancer without having any known risk factors.

Risk factors like diet, body weight, exercise, and smoking play a major role in many adult cancers. But these factors usually take many years to impact cancer risk, and they are

thought to have little or no effect on the risk of childhood cancers, including Wilms tumors. Most of the known risk factors for Wilms tumor cannot be controlled. They are genetic or hereditary (inherited).

A small number of children with Wilms tumor have a relative with the same cancer. These children may have inherited an abnormal gene from a parent. This gene change increases the risk of Wilms tumor, but it does not mean the child will have Wilms tumor.

There is a strong link between Wilms tumors and certain kinds of birth defects. About 1 out of 10 children with Wilms tumor also have birth defects. Most birth defects linked to Wilms tumors occur in *syndromes*. Syndromes are groups of symptoms or problems that are often linked to certain changes in genes. A part of a gene or even a whole gene may be missing. These missing or changed genes can cause Wilms tumors and other birth defects.

But most children with Wilms tumors do not have any known gene changes or birth defects. We cannot explain why they develop these tumors. There is nothing their parents could have done to prevent the cancer.

Can Wilms tumor be prevented?

Right now there is no known way to prevent Wilms tumors. Experts think the cancer comes from cells in the fetus that failed to grow into mature kidney cells. This doesn't seem to be caused by anything that a mother could avoid.

How is Wilms tumor found?

Wilms tumors are most often found when they start to cause symptoms like swelling in the belly, but by this point they have often grown quite large. They can be found earlier with tests such as an ultrasound (a test that uses sound waves and a computer to make pictures of your insides). But because Wilms tumors are so rare, it doesn't make sense to do ultrasound exams if a child has no Wilms tumor risk factors. There are no blood tests or other tests that are useful in looking for Wilms tumors in healthy children.

On the other hand, looking for Wilms tumor is very important for children who have syndromes or birth defects known to be linked to this disease. Most doctors recommend exams and ultrasound on a regular basis (maybe every 3 months until the child is 7 or 8 years old) to find any kidney tumors early – when they are small and have not spread to other organs.

Signs and symptoms of Wilms tumor

Wilms tumors can be hard to find early. They sometimes grow quite large without causing any symptoms. Children may look healthy and seem normal. The first sign is usually a swelling or hard lump in the belly. Chances are parents will notice the swelling. Some children may also have other symptoms such as:

- Stomach pain
- Fever
- Sick stomach (nausea)
- Not wanting to eat
- Constipation
- Blood in the urine

But other things often cause these symptoms, so they do not always mean your child has a tumor. Still, if your child has symptoms, check with your child's doctor so that the cause can be found and treated, if needed.

If there is any reason to suspect Wilms tumor, the doctor will ask questions to check for risk factors and symptoms. A physical exam can give more information about possible signs of Wilms tumor and other health problems. After that, the doctor may want to do tests to find out if there is a tumor.

Imaging tests

If the doctor thinks your child might have a kidney tumor, he or she will likely order one or more imaging tests. These tests make different types of pictures of organs inside the body. Imaging tests may be done:

- To find out whether there is a tumor in the kidney and if it likely to be a Wilms tumor
- To learn how far the tumor may have spread
- To help guide surgery or radiation therapy
- To see if treatment is working

These are some of the imaging tests that may be done:

Ultrasound: This test uses sound waves to make pictures of the inside of the body. The echoes made by most kidney tumors look different from those of normal kidney tissue. This is often the first test done if the doctor thinks your child may have a Wilms tumor. An ultrasound is painless and allows the doctor to see the whole belly (abdomen). Ultrasound is also very useful when looking for tumor growing into the main veins around the kidney. This helps doctors know how much surgery may be needed.

CT (computed tomography) scan: This test uses x-rays to take many pictures of the body. The pictures are then combined by a computer to give a detailed cross-sectional image. A CT scan is one of the most useful methods of finding a mass inside the kidney. It is also used to see whether the cancer has spread beyond the kidney.

Your child will need to lie still on a table while the scan is being done. During the test, the table slides in and out of the scanner, a ring-shaped machine that surrounds the table. Some people feel a bit confined by the ring they have to lie in while the pictures are being

taken. Some doctors may give younger children medicine to help keep them calm or even asleep during the test. *Spiral CT* is now used in many places. This type of CT scan uses a faster machine.

Your child may be asked to drink a contrast dye or have a contrast dye put into a vein. This helps better outline organs in the body. The dye may cause some flushing (a feeling of warmth, especially in the face). Some people are allergic and get hives. Rarely, more serious reactions like trouble breathing or low blood pressure can happen. Be sure to tell the doctor if your child has any allergies or has ever had a reaction to any dye used for x-rays.

MRI (magnetic resonance imaging): MRI uses radio waves and strong magnets instead of x-rays to take pictures. Like CT scans, MRIs show a cross-section of the body, but in more detail. This can help doctors see if the cancer is in a major blood vessel near the kidney. They may also be used to look for possible spread of cancer to the brain or spinal cord if doctors are concerned the cancer may have spread there.

MRI scans take longer than CT scans – often up to an hour. Your child has to lie inside a narrow tube and the machine also makes buzzing and clicking noises that may be disturbing. Your child may be given drugs to help him or her relax or sleep during this test. Newer, more open MRI machines may be another option for some children.

Chest x-ray: Chest x-rays are used to see whether the Wilms tumor has spread to the lungs.

Bone scan: For this test, a small amount of radioactive material is put into a vein. It collects in areas of diseased bone and can be seen with a special camera. This can help find cancer that has spread to the bones. This test may be done if the doctor thinks your child has a type of Wilms tumor that is likely to spread.

Lab tests

Certain blood tests are done to count the number of white blood cells and red blood cells and to measure other substances in the blood. Urine may be tested, too. These tests are not used to find Wilms tumor, but they give an idea of the child's overall health. They also provide clues about how well the liver and kidneys are working.

Kidney biopsy/surgery

In most cases, imaging tests tell doctors enough to decide whether your child has a Wilms tumor. But the only way to know for sure is when a piece of the tumor is removed and checked under a microscope. This is called a *biopsy*. It will also tell whether the tumor has favorable or unfavorable histology. (See the section "What is Wilms tumor?" for more on histology.)

In most cases, the biopsy is done during surgery to treat the tumor (see the "Surgery" section). Less often, a biopsy is done with a long, hollow needle as a separate test before surgery.

Staging for Wilms tumor

Staging is the process of finding out how far the cancer has spread. This is very important because your child's treatment and long-term outlook depend on the stage of the cancer.

The staging system used for Wilms tumor is called the NWTSG (National Wilms Tumor Study Group) system. It uses 5 stages of Wilms tumor. These stages are given Roman numerals I - V (1-5). The system takes into account findings from the physical exam, pictures from CT scans or other tests, and results of surgery (if surgery was done). In general, the lower the number, the less the cancer has spread. A higher number, such as stage IV (4), means a more advanced cancer.

After looking at the test results, the doctor will tell you the stage of your child's cancer. Be sure to ask your doctor to explain the stage in a way you understand. This will help you both decide on the best treatment.

Survival rates for Wilms tumor

Some parents of children with cancer may want to know the survival rates for their type of cancer. Others may not find the numbers helpful, or may even not want to know them. Whether or not you want to read about survival rates is up to you.

The survival rate for children with Wilms tumor varies with the stage of the tumor. It also depends on the histology of the tumor cells (how they look under a microscope). Ask your doctor to explain the stage and the histology of your child's cancer.

The 4-year survival rate refers to the percentage of children who live *at least* 4 years after their cancer is found. Of course, many children live much longer than 4 years (and many are cured).

In order to get 4-year survival rates, doctors have to look at children who were treated at least 4 years ago. Improvements in treatment since then may result in a better outlook for children now being diagnosed with kidney tumors. Also, some of these numbers are based on only a small number of cases, so their accuracy is not certain.

Wilms Tumor 4-year Survival Rates

Stage	Favorable histology	Unfavorable histology
I	99%	83%
II	98%	81%
III	94%	72%

IV	86%	38%
V	87%	55%

While statistics give an overall picture, keep in mind that every child's situation is unique and the numbers can't predict exactly what will happen. Talk with your cancer care team if you have questions; they know your child's situation best.

How is Wilms tumor treated?

This information represents the views of the doctors and nurses serving on the American Cancer Society's Cancer Information Database Editorial Board. These views are based on their interpretation of studies published in medical journals, as well as their own professional experience.

The treatment information in this document is not official policy of the Society and is not intended as medical advice to replace the expertise and judgment of your cancer care team. It is intended to help you and your family make informed decisions, together with your doctor.

Your doctor may have reasons for suggesting a treatment plan different from these general treatment options. Don't hesitate to ask him or her questions about your treatment options.

About treatment

About 9 out of 10 children with Wilms tumor are cured. Much of the progress in treatment is because of the work of the National Wilms Tumor Study Group (now part of the Children's Oncology Group). This group sets up clinical trials of new treatments for most children with Wilms tumor in the United States.

After your child's Wilms tumor is found and staged, the doctor will suggest a treatment plan. Most children with this cancer are treated as part of a clinical trial to try to further improve on what doctors believe is the best treatment. The goal of these studies is to find ways to cure as many children as possible with the fewest side effects.

Because Wilms tumors are rare, few doctors outside of those in children's cancer centers have much experience treating it. A team approach that includes the child's pediatrician as well as experts at the cancer center is recommended. If you decide to get a second opinion, it should be done quickly because Wilms tumors are usually very large and tend to grow fast.

Treatment for Wilms tumor most often means surgery, chemotherapy, and sometimes radiation treatment. The first goal of treatment is to remove the main tumor, even if there are distant areas of spread (metastases). If any cancer remains after the first operation, radiation therapy or more surgery might be needed.

Sometimes the tumor may be too large to be removed. It may have spread into nearby blood vessels or other vital structures, or it may be in both kidneys. In these cases, doctors might use chemotherapy or radiation therapy (or both) to shrink the tumor before trying to remove it.

Surgery for Wilms tumor

Surgery is the main treatment for Wilms tumor. It should be done by a doctor who is an expert in operating on children. Also, it's better if the surgeon has experience treating these cancers.

Removing the tumor

The main goal of surgery is to remove the Wilms tumor. Different operations may be used.

Radical nephrectomy: This is the most common operation for Wilms tumor that is only in one kidney. The cancer and the whole kidney are removed as well as the ureter, the adrenal gland, and some fatty tissue around the kidney. The surgeon may also remove lymph nodes (small, bean-sized collections of immune system cells that help the body fight infections) next to the kidney since cancer often spreads to these nodes. Most children can live very well with only one kidney.

Partial nephrectomy (nephron-sparing surgery): In the small number of children who have Wilms tumor in both kidneys, the surgeon will try to save some normal kidney tissue, if possible. The kidney containing the most tumor is often removed. In the other kidney the surgeon may try to take out just the tumor and a rim (margin) of normal tissue, which is known as a *partial nephrectomy*.

In some cases, both kidneys may need to be removed. This means the child will need to be on dialysis, which involves using a machine to filter waste products out of the blood several times a week. Once the child is healthy enough and a donor kidney becomes available, a kidney transplant might be done.

Finding out the extent of the disease

During surgery the doctor will look at the liver and the other kidney and may take samples of any areas of concern. These samples will be looked at under a microscope to see if they contain cancer cells. Lymph nodes near the kidney may also be removed at this time. (Lymph nodes are bean-shaped collections of immune cells that normally fight infection. Cancer often spreads to lymph nodes.) Knowing whether or not a Wilms tumor has spread is important in finding its stage and choosing further treatment.

Putting in a port (central venous access line)

If chemotherapy is to be given, the surgeon may talk to you about putting a small plastic tube (called a venous access device or port) into a large blood vessel. The end of the tube may be just under the skin or sticking out of the skin of the chest area or upper arm. This port is used to take blood samples and to give chemo and other medicines, as well as blood transfusions. It cuts down on the number of needle sticks needed. Someone on your cancer care team will teach you how to care for your child's port

Risks and side effects of surgery

Problems during surgery such as bleeding, damage to major blood vessels or other organs, or reactions to the drugs (anesthesia) used are rare, but they can happen.

Problems after surgery are rare, too. They can include bleeding inside the body (internal bleeding), infections, or problems with food moving through the intestines. Almost all children will have some pain for a while after the operation, although this can often be helped with medicines. If there are tumors in both kidneys, another concern is the loss of kidney function. In these cases, doctors must strike a balance between making sure the tumors are removed completely and removing only as much tissue as is needed.

For more information on surgery as a treatment for cancer, see our separate document, *Surgery*.

Chemotherapy for Wilms tumor

Chemotherapy ("chemo") is the use of drugs to kill cancer cells. The drugs are given into a vein or by mouth (in pill form). Once the drugs enter the bloodstream, they go throughout the whole body. This makes chemo especially useful for cancer that has spread beyond the kidney.

Chemo is usually given after surgery. Sometimes it may be needed before surgery to shrink a tumor to make the operation possible.

Chemo drugs are given in different combinations and strengths and at different times, depending on the stage of the tumor and the child's age. They are usually given by a nurse in the doctor's office or in the outpatient section of the hospital. In some cases, children with Wilms tumors stay in the hospital while they are getting chemo, but usually this is not needed.

Possible side effects of chemo

These drugs can have some side effects, depending on the type of drugs, how much is given, and how long they are given. Short-term side effects could include:

- Nausea and vomiting
- Not wanting to eat (loss of appetite)
- Mouth sores and pain
- Diarrhea or constipation
- Weakness, tingling, numbness in the arms and legs
- Hair loss (the hair grows back after treatment ends)
- An increased chance of infection (from a shortage of white blood cells)

- Bleeding or bruising after minor cuts or injuries (from a shortage of blood platelets)
- Tiredness or shortness of breath (from low red blood cell counts)

These side effects go away when treatment is over, but be sure and talk to the doctor if your child has problems. Often there are ways to help. For example, there are drugs that can be taken at the same time as the chemo to lessen or prevent nausea and vomiting.

Long-term side effects: The possible long-term effects of treatment can be a major challenge facing children after cancer treatment. For instance, if your child is given doxorubicin (Adriamycin[®]), there is a chance it could damage his or her heart. Your child's doctor will carefully watch the doses used and will check your child's heart function. Chemo can also increase your child's risk of getting a second type of cancer in the future. But the importance of treating Wilms tumor far outweighs these risks. See the section, "Moving on after treatment" for more on the possible long-term effects of treatment.

To learn more about chemo, see the American Cancer Society document, *Understanding Chemotherapy: A Guide for Patients and Families*.

Radiation therapy for Wilms tumor

Radiation treatment is the use of high energy rays (such as x-rays) to kill cancer cells or shrink tumors. External beam radiation is given in a way much like the x-rays used to find broken bones. The total dose of radiation is broken into small amounts given over many days. Each session involves having your child lie on a special table while a machine delivers the radiation. The treatment does not hurt. Each session lasts about 15 to 30 minutes, with most of the time being spent making sure the radiation is aimed correctly. Some younger children may be given medicine to make them drowsy before each treatment.

This type of radiation is often used along with surgery for more advanced Wilms tumors (stages III, IV, and V) and for some earlier stage tumors with unfavorable histology. (See the section "What is Wilms tumor?" for more on histology.)

Possible side effects of radiation therapy

Side effects from radiation can include nausea, diarrhea, tiredness, and sunburn-like skin changes. Often these will go away after a short while. Radiation can also cause a second cancer to develop or can damage other organs or tissues that are in the area being treated (the radiation field). But this usually doesn't happen because the amount of radiation used is low. Still, parents should have their child watched closely by doctors so that they can treat any problems quickly if they do come up. See the section, "Moving on after treatment" for more on the possible long-term effects of treatment.

To learn more about radiation treatment, see our document, *Understanding Radiation Therapy*.

Recurrent Wilms tumor

The outlook for children whose tumor comes back depends on what treatment they first had and the cancer's histology (how the cells look under a microscope).

The outlook is better for recurrent Wilms tumor if it has a favorable histology, was first found at an early stage, and did not require intense treatment.

The treatment for these children is surgery to remove the cancer if possible, then radiation and chemo (often with different drugs from those used during the first treatment).

Wilms tumors that do not have the features listed above are much harder to treat. Treatment for these children could be strong chemo or other drugs being studied in clinical trials. Very high-dose chemo followed by a stem cell transplant (sometimes called a *bone marrow transplant*) may also be an option.

Clinical trials for Wilms tumor

You may have had to make a lot of decisions since you've been told your child has cancer. One of the most important decisions you will make is deciding which treatment is best for your child. You may have heard about clinical trials being done for his or her type of cancer. Or maybe someone on your health care team has mentioned a clinical trial to you.

Clinical trials are carefully controlled research studies that are done with patients who volunteer for them. They are done to get a closer look at promising new treatments or procedures.

If you would like your child to take part in a clinical trial, you should start by asking your doctor if your clinic or hospital takes part in clinical trials. You can also call our clinical trials matching service for a list of clinical trials that meet your child's medical needs. You can reach this service at 1-800-303-5691 or on our Web site at www.cancer.org/clinicaltrials. You can also get a list of current clinical trials by calling the National Cancer Institute's Cancer Information Service toll-free at 1-800-4-CANCER (1-800-422-6237) or by visiting the NCI clinical trials Web site at www.cancer.gov/clinicaltrials.

There are requirements that must be met to take part in any clinical trial. If your child qualifies for a clinical trial, it is up to you whether or not to enter (enroll in) it.

Clinical trials are one way to get state-of-the art cancer treatment. They are the only way for doctors to learn better methods to treat cancer. Still, they are not right for everyone.

You can get a lot more information on clinical trials in our document called *Clinical Trials: What You Need to Know*. You can read it on our Web site or call our toll-free number (1-800-227-2345) and have it sent to you.

Complementary and alternative therapies for Wilms tumor

When your child has cancer you are likely to hear about ways to treat the cancer or relieve symptoms that your doctor hasn't mentioned. Everyone from friends and family to Internet groups and Web sites may offer ideas for what might help. These methods can include vitamins, herbs, and special diets, or other methods such as acupuncture or massage, to name a few.

What are complementary and alternative therapies?

It can be confusing because not everyone uses these terms the same way, and they are used to refer to many different methods. We use *complementary* to refer to treatments that are used *along with* regular medical care. *Alternative* treatments are used *instead of* a doctor's medical treatment.

Complementary methods: Most complementary treatment methods are not offered as cures for cancer. Mainly, they are used to help the patient feel better. Some examples of methods that are used along with regular treatment are meditation to reduce stress, acupuncture to help relieve pain, or peppermint tea to relieve nausea. Some complementary methods are known to help, while others have not been tested. Some have been shown not to help, and a few are even harmful.

Alternative treatments: Alternative treatments may be offered as cancer cures. These treatments have not been proven safe and effective in clinical trials. Some of these methods may be harmful, or have life-threatening side effects. But the biggest danger in most cases is that you may lose the chance to have your child helped by standard medical treatment. Delays or interruptions in medical treatments may give the cancer more time to grow and make it less likely that treatment will help.

Finding out more

It is easy to see why people with cancer think about alternative methods. You want to do all you can to help your child fight the cancer, and the idea of a treatment with few or no side effects sounds great. Sometimes medical treatments like chemo can be hard to take, or they may no longer be working. But the truth is that most of these alternative methods have not been tested and proven to work in treating cancer.

As you think about your options, here are 3 important steps you can take:

- Look for "red flags" that suggest fraud. Does the method promise to cure all or most cancers? Are you told not to have regular medical treatments? Is the treatment a "secret" that requires you to visit certain providers or travel to another country?
- Talk to your child's doctor or nurse about any method you are thinking of using.
- Contact us at 1-800-227-2345 to learn more about complementary and alternative methods in general and to find out about the specific methods you are looking at.

You always have a say in how your child is treated. If you want to use a non-standard treatment, learn all you can about the method and talk to the doctor about it. With good information and the support of your health care team, your child may be able to safely use methods that can help while avoiding those that could be harmful.

What are some questions I can ask my doctor about Wilms tumor?

As you cope with your child's cancer and cancer treatment, you need to have honest, open discussions with the doctor. You should feel free to ask any question that's on your mind, no matter how small it might seem. Here are some questions you might want to ask. Be sure to add your own questions as you think of them. Nurses, social workers, and other members of the treatment team may also be able to answer many of your questions.

- What kind of kidney cancer does my child have? Is it a Wilms tumor?
- Is the histology (appearance) favorable or unfavorable?
- Has the tumor spread beyond the kidney?
- What is the stage of the cancer and what does that mean?
- Are there other tests that need to be done before we can decide on treatment?
- How much experience do you have treating this type of cancer?
- What other doctors will we need to see?
- What treatment options do we have?
- What is the goal of this treatment?
- What do you advise and why?
- What are the short-term risks or side effects of treatment?
- What are the likely long-term effects of treatment? Could it make my child unable to have children?
- What should we do to be ready for treatment?
- How long will treatment last? What will it involve? Where will it be done?
- How will treatment affect our daily activities?
- Based on what you've learned about the cancer, what is the outlook for a cure?
- What are the chances of the cancer coming back with these treatment plans?
- What would we do if the treatment doesn't work or if the cancer comes back?

- What clinical trials are options for my child? Are these studies run by the Children's Oncology Group or a nationally known children's cancer center?
- What type of follow-up will my child need after treatment?

Add your own questions below. You might want to ask about health insurance coverage, getting a second opinion, or you may want more information about recovery times so you can plan your child's school schedule. You might also want to ask about nearby or online support groups, where you may be able to get in touch with other families who have been through this.

Moving on after treatment for Wilms tumor

After treatment for Wilms tumors, the main concerns for most families are the short- and long-term effects of the cancer and its treatment and concerns about whether the cancer might come back.

It is normal to want to put the cancer and its treatment behind you, and to get back to a life that doesn't revolve around cancer. But it's important to keep in mind that follow-up care is a key part of giving your child the best chance for long-term recovery.

Follow-up tests

Follow-up tests will include physical exams and tests like ultrasound and CT scans to look for the growth or return of the tumor, or any problems related to treatment. Since most patients have had a kidney removed, blood and urine tests will be done to see how well the remaining kidney is working. If your child had doxorubicin for chemo, the doctor may also order tests to check your child's heart.

The schedule for follow-up exams and tests depends on the stage of the cancer when it was found and its histology, or how it looked (favorable or unfavorable), as well as any problems the child may have had during treatment. Doctor visits will be more frequent at first, but the time between visits may get longer as time goes on.

During this time, it is important that any new symptoms be reported to your child's doctor right away, so that they can be treated, if needed. Your child's doctor can give you an idea of what to look for. If the tumor comes back, or if it does not respond to treatment, the doctors will talk to you about other treatment options.

Long-term effects of cancer treatment

Treatment for Wilms tumor has improved over the years, and more children are now living to become adults. While this is good news, it also has shown that childhood cancer treatment can affect the child's health as an adult. The results are known as *late effects*.

Careful follow-up after treatment allows doctors to watch for any late effects that show up. A child's risk for different late effects depends on a number of things such as what treatment they had and the age at which they were treated. Some of these late effects could include reduced kidney function, heart or lung problems, slow or decreased growth, changes in sexual development, and (rarely) getting a second cancer.

Ask your child's health care team about possible late effects and make sure there is a plan in place to watch for these problems and treat them, if needed. To learn more about these and other late effects, please see our document, *Childhood Cancer: Late Effects of Cancer Treatment*.

Most children with Wilms tumors were very young when their cancer was found. Still, some children may have emotional issues that need to be addressed during and after treatment. They might also have some problems with normal functioning and school work. There are often ways to help with these. Doctors and other members of the health care team can also often recommend special support programs and services to help children after cancer treatment.

Keeping good medical records

Once your child has grown up and is on his or her own, it is important other doctors have the details of the cancer diagnosis and treatment. There are certain things that your adult child's doctor should have. Make sure you have this information handy and always keep copies for yourself:

- A copy of the pathology report from any biopsies or surgeries
- A copy of the operative report if the child had surgery
- If the child was in the hospital, a copy of the discharge summary that the doctor prepared when the child was sent home.
- A list of the final doses of any chemo drugs the child was given. Certain drugs may have known long-term side effects. If you can get a list of these from the pediatric oncologist, it might help any new doctors your child has.
- If the child had radiation, a final summary of the dose and field

It is also important to keep health insurance. While you hope the cancer won't come back, it could happen. If it does, you don't want to have to worry about paying for treatment.

What's new in Wilms tumor research?

Much of the research going on in the area of Wilms tumor is being done through the Children's Oncology Group (COG). The group includes doctors, nurses, and scientists whose hard work has already saved the lives of thousands of children with Wilms tumor.

Biology of Wilms tumors

Research is going on to figure out how changes in certain genes cause Wilms tumors and why tumors with unfavorable histology do not respond well to treatment. As doctors have learned how to treat Wilms tumors better, they have begun to look for ways to figure out which children might be spared from more intensive treatment.

They are also looking for ways to spot children who might need stronger treatment to be cured. Recent studies have shown that Wilms tumors with certain changes on chromosomes 1 or 16 seem to be more likely to come back after treatment. Doctors are now looking at whether children with such tumors might be helped by more intense treatment.

Treatment of Wilms tumors

Clinical trials are also going on to improve treatment for children with Wilms tumor with fewer side effects. The goal is to give children no more treatment than is needed.

Recent studies suggest, for instance, that in some cases chemo may not need to be given for as long as was thought before. New drugs are also being studied. Other studies are looking at bone marrow transplants, which allow doctors to give high doses of chemo. This approach might help treat tumors that would otherwise have a poor outlook.

Researchers are also looking at the changes that seem to cause Wilms tumor cells to grow and spread. This may lead to treatments that are specifically designed to correct or overcome these changes.

More information about Wilms tumor

From your American Cancer Society

The following information may also be helpful to you. These materials may be ordered from our toll-free number, 1-800-227-2345.

After Diagnosis: A Guide for Patients and Families (also in Spanish)

Children Diagnosed With Cancer: Dealing With Diagnosis (also in Spanish)

Children Diagnosed With Cancer: Financial and Insurance Issues

Children Diagnosed With Cancer: Returning to School

Children Diagnosed With Cancer: Understanding the Health Care System (also in Spanish)

Clinical Trials: What You Need to Know (also available in Spanish)

Family and Medical Leave Act (FMLA)

Fertility and Cancer

Nutrition for Children with Cancer (also in Spanish)

Pediatric Cancer Centers (also in Spanish)

Surgery (also in Spanish)

Understanding Chemotherapy: A Guide for Patients and Families (also in Spanish)

Understanding Radiation Therapy: A Guide for Patients and Families (also in Spanish)

What Happened to You, Happened to Me (children's booklet)

When Your Brother or Sister Has Cancer (children's booklet)

When Your Child's Treatment Ends: A Guide for Families (booklet)

The following books are available from the American Cancer Society. Call us at 1-800-227-2345 to ask about costs or to place your order.

Because... Someone I Love Has Cancer (kids' activity book)

Caregiving: A Step-By-Step Resource for Caring for the Person with Cancer at Home

Childhood Cancer: Late Effects of Cancer Treatment

Jacob Has Cancer: His Friends Want to Help (coloring book for a child with a friend who has cancer)

Let My Colors Out (picture book for young children)

National organizations and Web sites*

Along with the American Cancer Society, other sources of information and support include:

American Childhood Cancer Organization (formerly Candlelighters)

Toll-free number: 1-800-366-2223

Web site: www.candlelighters.org

Cancer Kids

Web site: www.cancerkids.com

CureSearch (Children's Oncology Group and the National Childhood Cancer Foundation)

Toll-free number: 1-800-458-6223

Web site: www.curesearch.org

National Cancer Institute

Toll-free number: 1-800-422-6237 (1-800-4-CANCER)

Web site: www.cancer.gov

National Children's Cancer Society, Inc.

Toll-free number: 1-800-532-6459 (1-800-5-FAMILY)

Web site: www.children-cancer.org

Starlight Children's Foundation

Toll-free number: 1-310-479-1212

Web site: www.starlight.org

**Inclusion on this list does not imply endorsement by the American Cancer Society.*

Other publications*

For adults

100 Questions & Answers About Your Child's Cancer, by William L. Carroll and Jessica Reisman. Jones and Bartlett Publishers, 2004.

Cancer & Self-Help: Bridging the Troubled Waters of Childhood Illness by Mark A. Chester and Barbara K. Chesney. University of Wisconsin Press, 1995.

Care for Children and Adolescents With Cancer: Questions and Answers. National Cancer Institute. Available at: www.cancer.gov/cancertopics/factsheet/NCI/children-adolescents or call 1-800-332-8615.

Childhood Cancer: A Parent's Guide to Solid Tumor Cancers, by Honna Janes-Hodder and Nancy Keene. Published by O'Reilly and Associates, 1999.

Childhood Cancer: A Handbook from St Jude Children's Research Hospital by Grant Steen and Joseph Mirro (editors). Perseus Publishing, 2000.

Childhood Cancer Survivors: A Practical Guide to Your Future, by Nancy Keene, Wendy Hobbie, and Kathy Ruccione. O'Reilly and Associates, 2000.

Children With Cancer: A Comprehensive Reference Guide for Parents, by Jeanne Munn Bracken. Oxford University Press, 2001.

Educating the Child With Cancer: A Guide for Parents and Teachers, edited by Nancy Keene. Candlelighters Childhood Cancer Foundation, 2003.

Living With Childhood Cancer: A Practical Guide to Help Families Cope by Leigh A. Woznick and Carol D. Goodheart. American Psychological Association, 2002

Surviving Childhood Cancer: A Guide for Families, by Margot Joan Fromer. New Harbinger Publications, 1998.

When Bad Things Happen to Good People, by Harold Kushner. G.K. Hall, 1982.

When Someone You Love Is Being Treated for Cancer. National Cancer Institute. Available at: www.cancer.gov/cancertopics/when-someone-you-love-is-treated, or call 1-800-332-8615.

Young People With Cancer: A Handbook for Parents. National Cancer Institute, 2003. Available at: www.cancer.gov/cancertopics/youngpeople, or call 1-800-332-8615.

Your Child in the Hospital: A Practical Guide for Parents. (2nd Ed.), by Nancy Keene. O'Reilly & Associates. 1999. (Also available in Spanish)

Books for teens and children

These books are intended for children, but younger kids are helped more when an adult reads with and helps the child reflect about what different parts of the book mean to the child.

The Amazing Hannah, Look at Everything I Can Do! American Childhood Cancer Organization. www.candlelighters.org/Information/Resources/Books.aspx.

Chemo, Crazyness and Comfort, My Book about Childhood Cancer. American Childhood Cancer Organization. Available at: www.candlelighters.org/Information/Resources/Books.aspx.

Childhood Cancer Survivors: A Practical Guide to Your Future (2nd Ed.), by Kathy Ruccione, Nancy Keene, and Wendy Hobbie. Patient Centered Guides, 2006. For older teens.

Going to the Hospital, by Fred Rogers. Paperstar Book, 1997. For ages 4 to 8.

Life Isn't Always a Day at the Beach: A Book for All Children Whose Lives Are Affected by Cancer by Pam Ganz. High-Five Publishing, 1996. Workbook for ages 6 to 10.

Little Tree: A Story for Children with Serious Medical Problems, by Joyce C. Mills. Magination Press, 2003. For ages 4 to 8.

Living Well With My Serious Illness, by Marge Heegaard. Fairview Press, 2003. For ages 8 to 12.

Me and My Marrow, by Karen Crowe. Published by Fujsawa Healthcare, 1999. You can buy it as a book, but it's also available online at: www.meandmymarrow.com/book/toc_ie.htm. For teens.

My Book for Kids With Cansur [sic]. Gaes, Jason. Viking Penguin, New York, NY. 1998.

Oncology, Stupology...I Want to Go Home! by Marilyn K. Hershey. Butterfly Press, 1999. For ages 8 to 12. (Also available in Spanish.)

What About Me? When Brothers and Sisters Get Sick, by Allan Peterkin and Francis Middendorf. Magination Press, 1992. For brothers and sisters (ages 4 to 8) of a child with cancer.

When Someone Has a Very Serious Illness: Children Can Learn to Cope With Loss and Change, by Marge Heegaard. Woodland Press, 1991. For ages 6 to 12.

Why, Charlie Brown, Why? A Story About What Happens When a Friend Is Very Ill, by Charles M. Schultz. Ballantine Publishing Group, 1990. For ages 6 to 12.

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No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at **1-800-227-2345** or visit www.cancer.org.

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For additional assistance please contact your American Cancer Society
1 · 800 · ACS-2345 or www.cancer.org